

Self-Advocates and People Who Support Them:

Plan ahead for our 22nd Annual

Statewide Self-Advocacy Conference

2017 Conference Theme: "Self-Advocacy Round-Up"



Sponsored By: **Supported Life Institute**

- ~ Rich Environment of **Self-Advocacy & Peer Advocacy Education**
- ~ **Networking Opportunity** for Self-Advocates from all over Calif.
- ~ **Solid Training on a Wide Variety of Topics**

Keynote Speaker:
Russell Lehmann

"Western States Roundup"

For the 2nd year, we invite self-advocacy groups from nearby Western States Nevada, Hawaii, Arizona, Others!



Speaker / Author / Advocate

Member, Nevada Governor's Council on Dev. Disabilities
Board Member, Autism Coalition of Nevada

CONGRATULATIONS
to our partners at SABLE
(Self-Advocates Becoming Empowered)
for a grant from national
Administration for Community Living
in Washington DC to
create a 1st-ever
"National Resource Center
for Self-Advocacy"!

Fri-Sat, May 5 - 6, 2017 - Crowne Plaza Hotel
5321 Date Ave. (off Madison), **Sacramento**

Let us Know if you'd like to receive the Registration Materials !

----- (cut here)

Please send me the Flier in November 2016 and Registration Materials in February 2017. Number of copies? _____

Name _____ Phone (_____) _____

Address _____

City _____ State _____ Zip _____



Mail / Email Form: Supported Life Institute 1010 Hurley Way, Ste 180, Sacramento, CA 95825
info@supportedlife.org or FAX To: (916) 567-1977
Questions? (916) 567-1974 info@supportedlife.org
www.supportedlife.org





SAVE the DATES: OCTOBER 5 – 6, 2017

31st Annual SUPPORTED LIFE CONFERENCE:

Supported Life 2017:

*Empowering All People with Developmental Disabilities to be
Fully Included in the Community*

Crowne Plaza Hotel ~ Sacramento CA

Presented By Supported Life Institute & SCDD Sacramento Office

Hear a Variety of Important Speakers in the Field of Developmental Disabilities

Communication / AAC

Assistive Technology
Computer Access
Literacy
Speech-Generating Devices

Employment

Customized, Inclusive Employment
CMS Rules & Person-Centered Plans
Innovative Job Development
Microenterprise / Self-Employment
Natural Supports

Living / Community

Full Community Participation
Housing/ Accessible & Affordable
Individualized Support
Innovative Living Options
Transportation Issues

Organizational or Staff Development

Grant Writing
Fundraising
Staff Retention
Staff Training & HR
Organizational Restructuring

Personal Power & Rights

Advocacy & Self-Advocacy
Boardmanship & Facilitation
Criminal Justice Issues
Person-Centered Planning
Rights & Responsibilities
Making Your Own Choices

Policy & Legislation

Community Organizing
Meeting w/ Legislators / Lobbying
Political Action
Voting & Elections
Grassroots Advocacy

Relationships

Abuse Prevention
Friendships
Sexuality

This Conference is a place where professionals plus families & self-advocates come together to learn about supports that will help people with developmental disabilities be fully included in the community.

Transition

... To Independence
... To Jobs and Careers
... To Continuing Education
... To Adulthood & Adult Services
... From Early Start

“A Place to Train Your Staff - in an Inclusive Environment”

WarmLine is funded by:

**US Dept. of Education,
Office of Special Education**
Parent Training & Information (PTI) Center
(birth-26 years old)
to provide Special
Education support
in Region 5
(26 counties) of
Northern California.



Office of Special Education Programs
U.S. Department of Education

California Dept. of Developmental Services
Early Start Family Resource Center
(birth-3 years old) in Sacramento, Placer,
Yolo, El Dorado, Nevada & Alpine
Counties.

- **Child Action, Inc.**
- **Sacramento County First Five**
- **Sacramento County Office of Education**

**Generous donations from the community
through individual giving.**



Contact Us!

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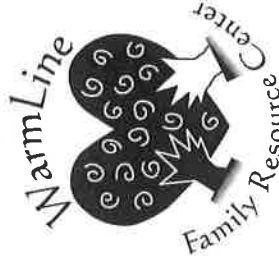
Open:

Monday-Friday: 9am - 5pm

Our Mission

Our mission is to provide information, education and support to promote and strengthen the foundation of families and children with special needs so they can face the challenges of the present and create new dreams for the future.

WarmLine is a public benefit
501(c)(3) nonprofit
organization and is grateful for your tax-
deductible donation which may be
made online at www.warmlinefrc.org
or by mail.



Providing
resources & support to families
of children and youth with
special needs.



www.warmlinefrc.org
Like us on Facebook

WarmLine Family Resource Center

is dedicated to offering support, information and referral (at no charge) to families of infants, children and youth with special needs and disabilities, birth to 26 years.

WarmLine is staffed by parents who share the experience of raising a child with special needs. Trained staff provide peer support to other parents and help them:

Connect with other families of children with special needs & disabilities,

Adapt to their new life and dreams for the future,

Navigate unfamiliar services, such as Early Intervention, Special Education, Regional Centers and Public Benefits,

Empower parents (and their children) to develop leadership skills and be active participants in their programs and services. Parents are their child's first teachers and best advocates!



WarmLine is a Parent Training & Information Center (PTI)

A PTI provides parents with information and training about:

- Disabilities;
- Parent and children's rights under Special Education (IDEA) and other relevant laws; and
- Resources in the community, state and nation.



WarmLine's trained staff provide individual consultation and can:

- Review documents related to Early Intervention, Special Education, etc.;
- Assist parents with strategies to prepare for Special Education (IEP) and other related meetings by setting priorities and goals;
- Support parents' collaborative communication skills.

Our Services

Family Support

Parent to Parent

Activities

Play Groups

Family Activities



Workshops/Seminars (English & Spanish)

Transition to Preschool
Special Education
Transition to Adulthood
Meeting of the Minds
And others...

Communication (English & Spanish)

Monthly email
Facebook and Pinterest

Publications (English & Spanish)

"Early Start Resource Guide"
"Turning Three"
"Understanding Special Education"
And others...

Information, Resources & Referral

Linking families with services

Website

Information on Early Intervention and Special Education

Outreach

Increasing public awareness of children with disabilities and available service

Bilingual (Spanish) Services

Staff members and publications

CalABLE: Providing People with Disabilities in California Greater Financial Security.

California Achieving a Better Life Experience (CalABLE) is a new program within the State Treasurer's Office that will allow people with disabilities to establish a tax-advantaged ABLE accounts that allow them to save up to \$14,000 per year and up to \$100,000 in total without losing vital public benefits such as Medicaid/Medi-Cal or SSI or SSDI. Earnings in these accounts are not subject to federal income tax or California state income tax, so long as the earnings are spent on "Qualified Disability Expenses" CalABLE began operations July 1, 2016 and plans to open for business by summer 2017.

BACKGROUND

In 2014, the President signed the Stephen Beck, Jr. Achieving a Better Life Experience Act of 2014 (IRC Section 529A), The law explicitly states the moneys in an ABLE account shall not be considered income, nor may the interest earned in an ABLE account be considered earned income for any means tested federal or state program.

Prior to the federal act, a person with a disability, receiving support from public benefit programs was not able to save more than \$2,000 without their SSI being suspended and any other asset accumulated would have been counted against them.

In 2015, the California State Legislature created the California Achieving a Better Life Experience Board (CalABLE or the Board) to implement the ABLE program in California.

Who is Eligible to Open an ABLE Account? An individual who has been diagnosed with a disability on or before age 26 may qualify by meeting one of the following:

- Is eligible to receive Supplemental Security Income (SSI);
- Is eligible to receive Social Security Disability Insurance (SSDI);
- Has been diagnosed by a qualified physician with a physical or mental disability resulting in marked and severe functional limitations that is expected to last no less than 12 months.
- An individual not eligible to receive SSI or SSDI may qualify based upon an impairment found within one of the following lists: <https://www.ssa.gov/compassionateallowances/conditions.htm>; <https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm>; <https://www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm>

What is a "Qualified Disability Expense"? An expense is qualified if it relates to the person's disability and helps them maintain or improve their health, independence, or quality of life. Qualified Disability Expenses are not restricted to just medical expenses. They can include rent and basic living expenditures such as expenses related to education, housing, transportation, employment support, health prevention and wellness, assistive technology, financial services, home improvement and funeral services.

Features and Benefits of an Account: The CalABLE Board is yet to determine many California specific features and benefits, but the following will be likely:

- Ability to contribute automatically through routine deductions from a banking or checking account;
- Ability to invite friends and family contribute directly to your account

- Deposit online or by check
- Interest earned on funds is tax free if used to cover qualified expenses
- Due to California's large population, fees will be the lowest in the country
- No impact on federal or state benefits
- Diverse investment options

Implementation Timeline: California plans to open its doors to participant's in the summer of 2017. In the meantime, along with setting up the internal infrastructure for this new state agency, staff will develop state regulations, hire consultant service providers, and design a Request For Proposal for a financial services vendor to design and implement the California program next summer.

Communications Plan: CalABLE will pursue a multi-prong outreach strategy that leverages existing state and local community networks of both public and private sector providers of services to Californians with disabilities, and potentially eligible individuals and their families. Our goal is to use these networks to first engage the community in the regulatory process and then to spread the word that ABLE is open for business. We plan to establish an advisory committee of state associations and advocacy groups that serve/advocate for people with disabilities. The goal of these committees will be to assist us in 1) ensuring that the regulations and program design meet the needs of our potential users, 2) educate their membership about ABLE; and 3) connect us to local and regional groups that can help spread the word. Finally, we also hope to utilize their communications networks to spread the word.

We're also planning on building a cadre of ABLE Ambassadors, people with disabilities and parents of children with disabilities, who are excited about ABLE and will commit to spreading the word about ABLE through their personal networks. We plan on developing materials for ABLE Ambassadors which they can post on their Facebook pages and get out through whatever social media they use. We'll also provide training on ABLE so that they feel comfortable spreading the word. We'll be looking to the regional/local groups to identify people whom they think would make good ABLE Ambassadors in their region.

Where we need your help:

- Identification of private and non-profit agencies, both state and local, who work with people with disabilities and their families who can help with outreach and education.
- How we might utilize the systems you have in place to communicate to the constituents you serve who would be eligible for an account.

Contact: Executive Director, Christina Elliott. Email: celliott@sto.ca.gov, (916) 653-4046

Like us on Facebook: <https://www.facebook.com/CalABLE>

Check out our Website: <http://www.treasurer.ca.gov/able/>

Take our Survey: <https://www.surveymonkey.com/r/CalABLE>

The Moment My Son With Down Syndrome Was Also Diagnosed With Autism

By Carrie Crockett

Contributor

I write about Autism Spectrum Disorder

From The Mighty 11/18/16

You walk outside with the psychiatrist into the spring sunshine of the clinic play yard. With all the testing over, what remains now are only the words. You watch your little one pass by sand toys, slide and swings to sit on a sunny patch of concrete.

In typical fashion, he picks up a leaf and begins to shake it back and forth. Back and forth. You take a second to admire his sweet face and the blue eyes that you adore. You hear the doctor shuffle her papers and pivot toward you. You turn as well, keeping your face unruffled and your mouth relaxed. Breathe. You admire her — the ironed white coat, the nice makeup. She looks up from her notes and begins to speak.

But before her words arrive, you blink into the slanting morning sunlight for a split second, and it occurs to you: This is my last second of not knowing. Although, really, you almost do know. You just don't want to hear her say it.

Definitely do not think of your husband, of your marriage, your other children, of your unfinished dissertation, of the avalanche that feels like it's gathering right above you. Forget about parent-teacher conferences and kids' volleyball games and what you were going to make for dinner tonight. It must all wait for now. Do not think about anything but getting through this moment.

Feel the sun.

She has begun: "Our testing process shows that your child has severe autism. His delays are not similar to those that most children with Down syndrome would normally experience." As she enters the thicket of explanation, you look carefully at her hazel eyes, at her short beautiful haircut, now being fluffed by the San Diego morning breeze. Your eyes move to her medical name badge, and you wonder how this kind of thing is for her, for only the two of you are present in this weighty moment that will change all the minutes and years that will come afterward. You look at her for what she truly is: the only other witness to the arrival of your changed life.

Her psychiatrist's manner is steady, even soft. She delivers the news with a practiced, compassionate firmness that suggests many such past encounters. You attempt to follow the direction of her words, which are now traversing alien, mountainous terrain. She briefly describes the methodology of her testing, the results of the classroom observations and what the teachers' assessments showed.

The voluminous pages of bubbled-in forms that you returned to her last month are acknowledged, as well as the results of his hearing tests. She begins to mention the details that you already know: his inability to imitate others or engage in imaginary play, his lack of a single

verbal or signed word despite his five years, the fact that he needs no more than four hours of sleep at night.

She repeats back to you the reality that you sometimes find him, inexplicably, outside the house in the mornings, whimpering on the cold lawn. A perplexing night wanderer who can open doors yet can't tell you why.

She talks about all of the things that he seems to not desire: friends, toys, compliments. That he has no apparent desire to show you a car he has unearthed from the depths of the sandbox or a dandelion plucked from the lawn.

Suddenly, you realize she is describing your life with him in such vivid, choking detail that you wish she would stop. Your chest tightens. She stops talking and looks at your face.

As you observe your child, who is still crouched in the play yard, shaking a leaf before his fathomless eyes, you realize that soon this moment of encounter with the white-clad psychiatrist will be over. She will be gone, and you will be left alone with the full weight of her words.

Resist the temptation to cue the heroic narrative, no matter how much you might need it. And refuse to panic, yet. There will be time enough for both heroism and panic later. For now, stay focused on the matter at hand. Release your breath and feel the sun.

She is about to shake your hand and walk back to her office — and you to your car and your now changed life. Before you both do, ask her: What is the best advice she can give? Listen as she tells you that you're going to need to establish a community of caregivers to help you, and that creating a new email account devotedly solely to his diagnosis might be helpful. Take the cards of the educational advocates that she offers. Make special note of the way in which she describes autism as a vehicle for getting him services that you now know he will not progress without. Hoard these snippets carefully, for although they do not comfort you, they are the best that she knows and here you will begin.

In the car, buckling his car seat, you realize this is ground zero, the beginning of the new, unwanted thing that — now known — might lead to help. All at once, you remember another morning, five years ago, when you were also in the car, when the phone rang and it was the genetic specialist on the line to tell you that the results of the amnio were in and your baby had Down syndrome.

You drive home. Get a Diet Coke. Lie on your bed. You cry while you watch him shake a spatula back and forth, back and forth, before his eyes while crouching in the corner of your room.

Don't rush, but when you are ready, think back on the day of the amnio when you were pregnant with him. The day they took the sample they would use to test for Down syndrome. Recall the feeling that you had as they pushed the long needle through your skin and into your belly; how as you looked at his small silhouette on the ultrasound screen and all you could think was, "Hey, it is OK, I love you. I love you even if. I love you anyway."

Realize, suddenly, that it is still true.